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ABSTRACT

This practicum was designed to alleviate feelings of isolation experienced by parents and extended family members of 17 primary students with severe emotional disturbance (SED). Practicum activities included biweekly educative and social support workshops for the parents and extended family members; an educative newsletter; pre-implementation and post-implementation surveys of all participants; a library of books and periodicals for participants; facilitation of a peer "buddy system"; and dissemination of information about medical, psychological, and social resources within the community. The practicum resulted in 15 extended family participants receiving information and support pertaining to issues surrounding the child's disability. The participants exhibited an improved attitude in coping with the disability, and 11 of them demonstrated an improvement in their emotional reactions to the disability. Appendices contain copies of various survey forms. (Contains 36 references.) (JDD)

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A Program Designed and Implemented to Alleviate Feelings of Isolation for the Extended Families of Primary, Severely Emotionally Disturbed Children Through an Educative and Social Support Network.

by

Sheila Halpin

Cluster 40

A Practicum II Report Presented to the
Ed.D. Program in Child and Youth Studies
in Partial Fulfillment of the Requirements for
the Degree of Doctor of Education.

NOVA UNIVERSITY

1994

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PRACTICUM APPROVAL SHEET

This practicum took place as described.

Verifier: Michelle D. Scanlon
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Bradenton, Florida

May 16, 1994

This practicum report was submitted by Sheila Halpin under the direction of the adviser listed below. It was submitted to the Ed.D. Program in Child and Youth Studies and approved in partial fulfillment of the requirements for the degree of Doctor of Education at Nova University.

Approved:

July 26, 1994
Date of Final Approval of Report

Georgianna Lowen
Georgianna Lowen, Ed.D.
Adviser

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I would like to acknowledge and dedicate this practicum to the influential women of my life:

My grandmother, Loretta, for accepting me as her own;

My Aunt Mary, for her sense of humor;

My Aunt Fran, for her compassion;

My Aunt Karen, for her courage;

My adopted aunts, Lois and Norene, for their wisdom;

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and especially my mother, Margaret Ann, for her dedication, perseverance, and strength, which allowed me to dream, and whose love made that dream a reality.

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ABSTRACT

A Program Designed and Implemented to Alleviate Feelings of Isolation for the Extended Families of Primary, Severely Emotionally Disturbed Children Through an Educative and Social Support Network. Halpin, Sheila, 1994: Practicum Report, Nova University, Ed.D. Program in Child and Youth Studies. Parent/Education/Exceptional/Elementary/Community/ Social/Support.

This practicum was designed for the parents and extended family members of 17 primary Severely Emotionally Disturbed (SED) students to alleviate feelings of isolation regarding the child's disability. Various interventions were utilized to reduce feelings of isolation and promote educative and community resources. Educative and social support workshops were designed and presented for the parents and extended family members of the SED children in an Exceptional Student Education (ESE) classroom in a public elementary school. Participants received psychological, medical and social resources at no cost.

The writer facilitated bi-monthly educative and social support workshops for the parents and extended family members of the SED children; distributed an educative newsletter; administered pre-implementation and post-implementation surveys to all participants; provided a library of books and periodicals pertaining to various disabilities for participants; utilized medical, psychological and social resources within the community and facilitated a peer "buddy system".

Analysis of the data revealed that the 15 extended family participants in the educative and social support network program received information and support pertaining to issues surrounding the child's disability. The 15 participating families exhibited an improved attitude in coping with the SED child's disability. Of the 15 extended families participating, 11 demonstrated an improvement in their emotional reactions to the disability.

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CHAPTER I

INTRODUCTION

Description of Work Setting and Community

The school in which this practicum was conducted was a suburban elementary school. The school is situated in a middle socioeconomic area near city limits. Many attending students live in suburban areas within a close proximity to the school. The economic status of the families in this community ranges from low to middle income.

The population of the county in which the school is located was 211,000 as of the 1990 census, and is skewed toward people of retirement age. There are 25 pubic elementary schools serving this population.

The community has begun to address the needs of its residents through the adoption of a county-wide tax designated to provide children's services. Services rendered included child advocacy, family interventions, child development and education.

Writer's Work Setting and Role

The writer's work setting is in an elementary school serving prekindergarten through fifth grade. The enrollment is 721 students. Approximately 127 children receive bus transportation, with the majority of the students commuting from within a 2-mile radius. Demographics reveal 13% of the population is comprised of minority students.

The average regular education class size is 27, with the teacher-pupil ratio being 1:28. The average Exceptional Student Education (ESE) class size is 17, with the teacher-pupil ratio being 1:5.

The school, famed for community integration, is expanding the traditional classroom philosophy. Strategic plans contended that, within three years, it will function as a full-service school. The needs (educative, social and emotional) of the entire community will be identified and met through school intervention.

The writer is a seventh-year teacher-counselor of special education. The writer's class size averages 17 full-time, self-contained, Severely Emotionally Disturbed (SED) primary pupils. The writer provides counseling, assessment and development of age-appropriate strategies, crisis intervention and liaison work among administration and parents. The writer serves on the following committees: discipline, technology, public relations, school improvement plan, and crisis intervention. The writer's short-term goal

is to become an effective ESE coordinator and county administrator.

CHAPTER II

STUDY OF THE PROBLEM

Problem Description

The philosophical goal of ESE programming is to promote the emotional, social and behavioral growth, as well as the academic progress, of the exceptional child. Individualized educational programs are stressed with the goal of returning the child on a full- or part-time basis to a less restrictive environment or the mainstream.

The SED unit is not identifying or addressing the needs of the family. The exceptional child, and his disability, are the focus of the SED unit. The parents and extended family members of the disabled child are excluded from receiving educative or support services. This lack of family integration has contributed to feelings of isolation, frustration and confusion among family members.

The family unit has remained independent and segregated from services provided by the school and community. No resolution has been obtained for the family of the disabled child because the family's needs had not been deemed relevant by the educative or community resources.

In brief, the problem is that the parents and extended family members of the 17 disabled children encapsulated within the primary SED unit feel isolated in understanding their child's disability.

Problem Documentation

The stated problem, that the parents and extended family members of the 17 disabled children encapsulated within the primary SED unit feel isolated in understanding their child's disability, was supported by conversations, observations and an examination of the community.

Conversations between the parents of the 17 children in the SED unit and the writer revealed that the parents did not know how to cope with the emotional, social or personal needs of their child. They reported feelings of inadequacy and a frustration with the community's lack of resources for exceptional children.

Conversations between the SED unit's teachers and the writer revealed that the family was not addressed as an entire unit. Extended family members were often not privy to conversations regarding the disabled child. This lack of family involvement had caused inconsistencies between home and school, hindering the child's educative, emotional and social development.

An examination of the community by the writer (see Appendix A) revealed that local services did not provide advocacy, counseling, child development evaluations or

therapeutic support for the extended family of the disabled child (see Table 1). Of the 10 educative and support services polled, all addressed some combination of children and parents, but neither the extended family nor the disabled child received community services.

Causative Analysis

It is the writer's belief that there are three reasons for the problem that parents and extended family members of disabled children feel isolated in understanding their child's disability.

The entire family is not typically addressed when considering the needs of the child. The exclusion of family members contributes to a limited understanding of the disability, facilitates misconceptions regarding the disability and hinders family adjustment and acceptance. This lack of communication led to feelings of isolation.

A disabled child can impair family function and interaction and put increased demands on the family structure. The effects of the child's disability influence the family's socioeconomic status, interpersonal relationships, daily routines and future.

The psychological, medical and social fields have been working independently of each other and not addressing the needs of the family. This has led to conflicting information, miscommunication and a sense of frustration for the parents and extended family.

Table 1

Community Services Available

SERVICE TYPE	# of Agencies Addressing... Total # of Agencies	Disabled Children	Parents	Extended Families
Advocacy	3	0	3	0
Counseling	3	0	2	0
Child Development Evaluations	2	0	2	0
Support Groups	2	0	2	0

NOTE: 10 educative and support agencies in the community polled.

Relationship of the Problem to the Literature

A review of the literature provides evidence of the problem that the parents and extended family members of the disabled children feel isolated in understanding their child's disability.

The preliminary literature review showed Bernheim and Lehman (1985) and Wasserman (1983) discussing evidence of the problem that the parents and extended family members do not feel they are provided with enough educative information or social support pertaining to their child's disability. Feelings of isolation, frustration, anger, guilt and depression can occur.

Professionals in the medical, psychological and social fields can provide evidence of the problem as well as be potential causes. Robertson (1991) reports that professionals do not want to become involved in dealing with parents' feelings such as depression, isolation, denial and hostility.

A contributing factor to the problem is that professionals are not well informed about referral services in the community (Resnick, 1984). Parents hold the belief that professionals do not want to become involved with them or the difficulties associated with their child's disability (Rousso, 1985). Lazzari and Kilgo (1989) talk about the many professionals who do not take the initiative to guide parents toward helpful resources. This can contribute to frustration, anger and poor self-esteem. When parents

believe that professionals do not want to help, their feelings of isolation are increased.

The tendency to rely on labels instead of describing the strengths and weaknesses of a disabled child has a negative effect on the children and their parents, according to Todis and Singer (1991). In order to gain access to the best programs available, some parents even learn to manipulate the diagnosis of their child' s disability.

The attitudes of health professionals are also influential in the family's reaction to the disability. Avoidance of contact or response to the child by the professional implies to the parents that the child is not acceptable. This can add to the guilt and loss of self-worth parents feel (Runin and Quinn-Curran, 1983).

When confronted with a child's disability, Gargiulo (1985) identifies three stages of reaction. The primary phase is characterized by shock, grief and denial; the secondary phase by ambivalence, guilt, anger, shame and embarrassment; and the tertiary phase by bargaining, adaptation, recognition, acceptance and adjustment. Johnson (1991) affirms the stage theory as it applies to mourning, segmenting parental reaction into stages of grieving with guilt and shame among them.

As parents try to find a cause for their child's disability they will be overwhelmed by feelings of guilt and remorse, which in turn affects the family's adaptability (Bragg, 1992). The guilt felt by the parents of disabled

children can often be a product of their own feelings of inferiority and inadequacy.

The range of parental reactions to their child's disability include feelings of isolation, depression, anger and loneliness (McAneney, 1990). According to McCracken (1984), some of the more typical parental reactions to a child's disability are feelings of shame, defensiveness and loss of self-esteem.

Grandparents also experience a personal crisis at the birth of a disabled grandchild. The strains placed on a marriage by the birth of a disabled child are intensified by difficulties in communication between the parents and grandparents of the child. Feelings of disappointment or rejection hinder the acceptance of the disabled child ("Understanding Grandparents," 1988) .

When a disabled child lives with the family, he or she increases the demands placed on family functions without adding anything to their functional capacity (Turnbull, Summers and Brotherson, 1985). When a disabled infant is returned with its parents to the home after birth, family life is disrupted by additional stress and tensions (Noh, 1989). Dyson (1991), Hutliner (1988), and May (1992) concur that the parents of disabled children are under great amounts of stress. The uncommon needs of the disabled child cause tension for parents, siblings and the extended family.

The disabled child can also restrict the family's activities, reduce their earnings and alter the family's

self-identity. Having a disabled child at home has a profound effect on family life (Drotar, Crawford and Bush, 1984) and leads to social stigmatization by the community (Offer, Ostrov and Howard, 1984). This stigmatization can negatively affect the family's self-image.

Resentment is felt when a sibling must supervise, care for and protect the handicapped child (Murphy and Della Corte, 1989). These feelings are magnified when the sibling is neglected or deprived of opportunities in favor of the handicapped child. Sourkes (1987) discusses how increased anxiety levels in the family cause resentment, guilt and anger in siblings toward their handicapped brother or sister and toward their parents. DeLuca and Solerno (1984) believe that the siblings of a disabled child are at risk for future emotional disturbance.

Beckman (1983) discovered that disabled children who required an unusual amount of care or had special, uncommon needs caused significant stress for their mothers. Parents of severely handicapped children were under a significantly greater amount of stress than parents with regular education children.

The lack of support services for the family of a child diagnosed with a disability are lamented by Dysona and Fewell (1986). This lack of community resources contributes to the family's feelings of isolation, depression and anger.

The various topical areas researched were disabled children, disabilities, emotional disturbance, stress,

elementary school students, family, family function, isolation, elementary education, program descriptions, family involvement, intervention, primary education, interpersonal relationships, program evaluation, social development, depression, self identity, denial, community resources, special needs, developmentally inappropriate social behavior, social maladjustment, special education and coping skills.

CHAPTER III

ANTICIPATED OUTCOMES AND EVALUATION INSTRUMENTS

Goals and Expectations

It appears that the parents and extended family members of the 17 disabled children encapsulated within the primary SED unit are feeling isolated in understanding their child's disability. The goal of the writer is to alleviate the parents' and extended family members' feelings of isolation by providing an educative and social support network.

The writer expects parents and extended family members to have a better understanding of their child's disability and of the resources available to them.

Expected Outcomes

As a result of the 32-week intervention, the following goals and outcomes are projected for this practicum:

1. Of the 15 extended families, 10 will report on a family survey that they received information and support regarding issues surrounding their child's disability by providing examples in 7 out of 10 questions (Appendix B).

2. Of the 15 extended families, 10 will report an improved understanding of their child's disability by responding positively on at least 3 out of 4 questions in an interview questionnaire (Appendix C).
3. Of the 15 extended families, 10 will demonstrate that they have an understanding and knowledge of the medical, psychological, social and community resources available to them, and of how to obtain these resources, by responding positively to 7 out of 10 questions on a resource questionnaire (Appendix D).
4. Of the 15 extended families, 10 will report an improvement in their emotional reactions to the disability, specifically regarding feelings of isolation, depression, hostility and denial, and better coping skills by responding positively to five out of eight questions on an emotional reaction survey (Appendix E).

Measurement of Outcomes

Measurement techniques include surveys, questionnaires and interviews with the ESE team and parents. Subjective answers will be verified through specific examples provided by the respondents.

CHAPTER IV

SOLUTION STRATEGY

Discussion and Evaluation of Possible Solutions

The stated problem is that the parents and extended family members of the 17 disabled children encapsulated within the primary SED unit feel isolated in understanding their child's disability.

A careful review of the literature suggests several possible solutions to the stated problem including information and education for family members of the disabled child, professional and community intervention and support groups.

LaBorde and Seligman (1983) discuss the importance of providing information and education to the parents and extended family members of the disabled child. The acquisition of information regarding the disability can alleviate stress, reduce tension and dispel fallacies harbored by the family. Education regarding the future of the disabled child and educational and social services provided by the community will increase communication and understanding of the disability.

The most pervasive attitude toward the disabled is stigma. Recognition by the community and its professionals will reduce parents' feeling of helplessness during the early months after diagnosis. Professionals should be astute on community resources and be able to reference services and providers competent in the area of disability (Harris, 1983). Services identifying the needs of the extended family (Sonnek, 1986) have begun to be recognized as viable community needs. The acquisition of educative and community programming and professional recognition will alleviate stereotypes associated with the disability (Brantlinger, 1991).

The functions of a support group for the parents and extended family members of the disabled child include alleviating loneliness and isolation, providing information, providing role models and providing a basis for comparison. There is no greater need for the parents of the disabled child than to talk (Max, 1985). Minde (reported in Collins-Moore, 1984) found that parents who attended a support group had higher levels of interaction with their disabled children than parents who did not. Parent-to-parent support groups (Hornby and Murray, 1983) help to promote positive feelings toward the disabled child. A sibling support group (Reynolds and Zellmer, 1985) can encourage discussion pertaining to feelings and coping mechanisms currently employed by the family. Meyer and Vadasy (1986) report that

grandparents were lacking information and support in a number of areas. The facilitation of a grandparent's workshop was developed to address these concerns.

Support groups can assist with self-exploration and the disclosure of feelings. These groups can help parents and extended family members gain an awareness of attitudes and behaviors inflicted upon the disabled child. Coping skills and the families' hopes and expectations for the future can also be examined (Friedlander and Watkins, 1985).

Additional ideas which were explored by the writer include:

(1) A library of books and periodicals pertaining to disabilities for use by parents and extended families being established in the classroom;

(2) Family members having access to a list of medical, psychological and social resources available to them in the community;

(3) Encouraging the parents and extended family members to keep a journal regarding their feelings associated with the disabled child; and

(4) Encouraging the parents and extended family members to participate in a "buddy system," linking them with peers who will be available to provide support for each other when one is experiencing isolation or having difficulty coping at home.

Description and Justification for Solution Selected

The solution which the writer suggested to the problem was the implementation of an educative and social support network for the parents and extended family members of the disabled child.

As part of the SED curriculum, an educative and social support network was implemented to alleviate feelings of isolation. A workshop was developed to provide education and support for the parents and extended family members of the disabled child. The workshop curricula drew upon the suggested solutions in the literature, combining educative, psychological, medical and social fields in accordance with community resources.

The writer provided family members with the opportunity to participate in a networking group on a regular basis, to learn more about their child's disability. Extended family members were provided with an educative newsletter which addressed the child's special needs.

The rationale for each component of this educative and support network was based upon an analysis and evaluation of the literature reviewed.

It was hoped that this project would succeed because of four factors:

(1) The extended families of the children in the writer's SED unit have expressed an interest in learning

more about their child's disability and the resources available to them;

(2) The school principal and SED teachers at the writer's work site were supportive of efforts to educate and inform the families of the SED students;

(3) The parents and extended families of the children would benefit from exposure to psychological, medical and social professionals; and

(4) The writer's work site was easily accessible to the families of the children, located near major roadways and public transportation.

Procedures that were to be followed by the writer prior to implementation included:

(1) A discussion of the plan for implementation with the school principal and ESE Teacher-On-Assignment;

(2) Sharing the plan for implementation with the unit's teachers and Team Leader of Special Programming;

(3) Filing a copy of the proposal in the SED unit;

(4) Compiling a list of relevant educative and support materials;

(5) Deciding upon the schedule for the bi-monthly, half- to one-hour workshops and support meetings, after conferring with the SED unit;

(6) Identifying and recruiting speakers for the workshops; and

(7) Planning a presentation to explain the educative workshops, support plan and newsletter to the parents and extended family members during the first week of the implementation.

Report of Action Taken

The writer provided bi-monthly educative and social workshops for the parents and extended family members of 17 primary SED students.

Prior to Week 1

An introductory meeting was held with the parents and extended family members of the 17 primary SED students and the SED unit teachers to discuss coping skills, community resources and extended family involvement pertaining to the child's exceptionality. A pre-implementation examination of the community (Appendix A) was administered.

Week 1 of the period of implementation

A presentation was held for the parents and extended family members regarding the educative workshops, support group meetings, "buddy system" and newsletters. The writer defined the goals and anticipated outcomes of the practicum to the parents and extended family members.

Week 2 of the period of implementation

The first issue of the educative newsletter was written, produced and distributed. It reiterated the

goals of the program, explained the use of the library of resources which was established in the classroom and provided names and phone numbers for the "buddy system".

The newsletters were developed, published and distributed during the "even" weeks of the implementation, which will not be reiterated below due to confidentiality of the participants.

Week 3 of the period of implementation

The first regular support group meeting was held. Parents and extended family members were invited to share experiences and feelings associated with their child's disability. Parents and extended family members discussed their family systems (relationships, communication, attitudes and routines).

The follow-up discussion included differences in behavioral management techniques, feelings of inadequacy pertaining to the SED child's behaviors, feelings of anger and isolation and household responsibilities.

Flexibility and willingness to understand the quality of the extended family relationship with the parents of the disabled child was an extended topic of discussion. The parents who felt they had a good relationship with the grandparents of the disabled child felt receptive and were able to discuss their

feelings of anger, inadequacy and guilt, family discord and new management techniques with the family.

If, however, the grandparents had strict or rigid ideas regarding discipline, which contradicted the parents' management philosophy, a dilemma arose. Several parents of the disabled children had verbally requested that their parents not criticize them in front of the disabled child or to undermine their authority. The grandparents, who had a hard time accepting this request, were told by the parents that their visitation with the disabled child may have to be limited until resolution could be obtained for all participants. The grandparents criticism of the parents was working against what the parents were doing with the disabled child, which in turn affected the entire family unit.

A consensus was obtained that further dialogue would need to occur for several of the families for resolution to occur. Recommendations for "closure" from the group included a listing of local family therapists who would be qualified to assist with family communication.

Week 5 of the period of implementation

The first workshop was held. The SED teachers discussed realistic expectations for the disabled

child's progress in school and the relationship between school and parents.

The follow-up discussion included parent availability, teacher accountability, reinforcement in the home and parent-teacher cohesion.

Several parents voiced their concerns regarding their disabled child's academic progress. They did not comprehend the goal of the program and were concerned that their child was functioning below grade level.

One family questioned the educational credentials of the SED teachers. This family expressed that they had no management difficulties with their disabled child at home. When their disabled child reacted inappropriately at home he was "beat". This family expressed their disdain for "psychological jargon" and hypothesized that their child would have no difficulties in school if teachers were permitted to spank.

Recommendations for closure from the group included parents and extended family members taking a pro-active role in their child's classroom, provision of academic homework and home intervention, both rewards and/or consequences for daily school behavior.

Week 7 of the period of implementation

The next regular support group meeting was held. Parents and extended family members discussed the child's handicap and how these problems affect the family. Parents and extended family members discussed the effects of their child's disability on such sociocultural factors as socioeconomic status, employment and religion.

The follow-up discussion included lack of community resources for respite and before and after school child care, unavailability of funding, high cost of medical intervention, psychological assessments and therapeutic sessions for the individual, immediate and extended family members.

The mothers of the disabled children verbalized feeling bewilderment, exhaustion, anger, guilt, embarrassment, inadequacy, depression, isolation, victimization and a lack of satisfaction.

The fathers of the disabled children questioned the mothers' approach, expressed feelings of jealousy toward the disabled child due to the mothers' attention and expressed feeling isolated due to lack of involvement with the mother and/or disabled child.

Financial and job pressures, due to the disabled child, affected the entire family structure. Families

voiced concerns regarding expenditures for the disabled child, absenteeism due to the disabled child's inappropriate behaviors and their ripple effect on the entire family.

Week 9 of the period of implementation

The second workshop was held. A physician explained the medical implications of the children's disabilities.

The follow-up discussion included the physiological conditions that would or would not merit medication, the implications of various forms of medication and their side effects and the effectiveness of a behavioral modification treatment plan.

Week 11 of the period of implementation

The next regular support group meeting was held. Parents and extended family members discussed their feelings of isolation and how they may be overcome. Parents and extended family members discussed their feelings of depression and how they may be overcome.

The follow-up discussion included displacement of anger and aggression, family conflicts, household responsibilities, sibling confrontation, sibling understanding, therapeutic communication, family cohesiveness and therapeutic interventions to deal with isolation and depression. Examples were given by

participating families as to the resolution of depression in their households.

One of the participating families discussed their need of "down time" from the disabled child. The siblings of the disabled child received one special activity per week without the disabled child. The parents of the disabled child, once a month, went on a "date" without any of their children. This "down time" has helped this family to alleviate some of the depressed feelings they had experienced.

An extended family member, who also instructs aerobic and cardiovascular activities at a local gym, offered free weekly guest passes to program participants. Babysitting services at the gym were provided free of charge. Her rationale for the provision of the passes included "exercise and movement is not only good for the body, but good for the mind as well."

Week 13 of the period of implementation

The third workshop was held. A physical therapist discussed exercise and motor skills that may be helpful with the children.

The follow-up discussion included fine and gross motor development, delayed development and physical activities which included immediate and extended family member participation. The importance of regular and

consistent physical integration into one's daily schedule was stressed. Resources were indicated.

One of the participating families suggested extracurricular exercise, in a group format, would be beneficial for the disabled children, since no local group provisions were available.

Kickball games and picnics were held one Saturday a month until the completion of program implementation. Each family brought a covered dish to the picnic and one of the extended family members, who operated a local convenience store, provided beverages.

This Saturday picnic increased group cohesiveness, family participation and assisted with the development of motor skills for all participants.

Week 15 of the period of implementation

The next regular support group meeting was held. Parents and extended family members discussed the stress on family relationships attributed to the disability of the child. Parents and extended family members discussed expectations for their child for the future.

The follow-up discussion included high levels of stress in the family, economic and marital concerns and sibling and extended family members' feelings of guilt. Expectations for the future were discussed. Very low expectations for the handicapped child has contributed

to feelings of frustration and guilt. One quarter of the participants indicated that they felt their child would not be a productive member of society, thus the burden of family responsibility would be continued.

Week 17 of the period of implementation

The fourth workshop was held. A psychologist discussed problems of management of emotional reactions and assisted parents and extended family members with comprehension of their emotional reactions.

The follow-up discussion included feelings of anger, guilt, isolation, frustration and depression. Therapeutic techniques and interventions were discussed to assist with the alleviation of these feelings.

An extended family member shared that he instructed yoga at a local community college and program participants were invited to participate in his class free of charge. Babysitting services were provided for the disabled children.

Week 19 of the period of implementation

The next regular support group meeting was held. Parents and extended family members discussed coping skills: what is currently utilized and what is effective. Parents and extended family members discussed ideas for coping more effectively in the future.

The follow-up discussion included extended family member support, behavioral modification strategies to be utilized in the home of the SED child, the importance of "down" time for family members and provision of respite care for the families.

One idea which was suggested by the parents of a disabled child included the facilitation of a respite program. One of the extended family members volunteered to coordinate a respite "buddy" program. Those choosing to participate gave their names and telephone numbers to the "coordinator". She then developed a respite network. For each hour of respite received one would have to be given. The respite hours were acquired for the disabled child and it's family. Therefore, extended family members could provide respite for another disabled child and bank that hour in the name of their family's disabled child. This respite program is still in effect.

Week 21 of the period of implementation

The fifth workshop was held. An ESE representative explained parental rights and elaborated on legal aspects of the children's disabilities.

The follow-up discussion included confidentiality, availability of resources, an overview of State and Federal laws and Due Process procedures.

Week 23 of the period of implementation

The next regular support group meeting was held. Parents and extended family members discussed what it is like to have a disabled child in the family, specifically stimulating conversation with siblings, grandparents and extended family members. Extended family members discussed feelings regarding the disabled child.

The follow-up discussion included feelings of anger, denial, guilt, acceptance and understanding of the SED child's handicap. All extended family members shared that they experienced feelings of isolation regarding the decision-making process for the child.

Week 25 of the period of implementation

The sixth workshop was held. A social worker discussed additional resources, including government programs regarding disabled children, and how they may be accessed.

The follow-up discussion included government subsidies, medicaid, Social Security benefits and sliding-scale fees for medical and therapeutic interventions. Not-for-profit organizations were identified.

Week 27 of the period of implementation

The next regular support group meeting was held. Parents and extended family members discussed crisis intervention. Parents and extended family members developed a strategy to respond to a crisis.

The follow-up discussion included the utilization of a "buddy system" and cool-down area, availability of emergency numbers and knowledge of how to use them and development of an emergency plan and it's implementation.

Week 29 of the period of implementation

The seventh and final workshop was held. A family counselor discussed the impacts of the special needs child on the entire family structure.

The follow-up discussion included an evaluation of family roles, the need to make the disabled child accountable, the importance of communication for the entire family, realistic expectations for the disabled child and family support for each other.

Two couples shared that they felt the stress from their disabled child had begun to contribute to the demise of their marriages. One of these couples was contemplating divorce. The family counselor offered to waive her fees and provided marital counseling to those families in crisis.

Week 31 of the period of implementation

The next regular support group meeting was held. Parents and extended family members discussed advocacy and developing partnerships between the families of the disabled and professionals. Parents and extended family members began to network within the community. A wrap-up discussion of the program and information learned was presented.

Week 33 of the period of implementation

Post-implementation assessments were administered and evaluated.

The implementation went smoothly and according to schedule. It was clear that, with the support and participation of the family members and SED team, and community resources, the time line designed was feasible.

CHAPTER V

RESULTS, DISCUSSION, AND RECOMMENDATIONS

Results

The problem is that the parents and extended family members of the 17 disabled children encapsulated within the primary SED unit feel isolated in understanding their child's disability. This lack of family integration has contributed to feelings of isolation, frustration and confusion.

The results of the educative and social support network used were analyzed in a comparative mode and through analysis of specific examples provided by the respondents.

Outcome No. 1

As a result of the 33-week implementation phase of the educative and social support network, of the 15 extended families, 10 will report on a family survey that they received information and support regarding issues surrounding their child's disability, by providing examples in 7 out of 10 questions (Appendix B).

Results

The outcome measure was met and exceeded. The 15 participating families surveyed responded positively regarding receiving information and support pertaining to issues surrounding their child's disability. The extended families were able to provide specific examples for all questions asked (see Table 2).

Outcome No. 2

As a result of the 33-week implementation phase of the educative and social support network, of the 15 extended families, 10 will report an improved understanding of their child's disability by responding positively on at least three out of four questions in an interview questionnaire (Appendix C).

Results

The outcome measure was met. The post-implementation results revealed that all participating families felt they had an improved understanding of their child's disability, more realistic expectations for their child's capabilities and an understanding of the medical, psychological and social services available (see Table 3).

Outcome No. 3

As a result of the 33-week implementation phase of the educative and social support network, of the 15 extended families, 10 will demonstrate that they have an

understanding and knowledge of the medical, psychological, social and community resources, by responding positively to 7 out of 10 questions on a resource questionnaire (Appendix D).

Results

The outcome measure was met. The post-implementation results revealed that all participating extended families had a greater understanding of community resources and were able to provide specific examples for utilization. (See Table 4).

Outcome No. 4

As a result of the 33-week implementation phase of the educative and social support network, of the 15 extended families, 10 will report an improvement in their emotional reactions to the disability, specifically regarding feelings of isolation, depression, hostility and denial, and better coping skills, by responding positively to five out of eight questions on an emotional reaction survey (Appendix E).

Results

The outcome measurement was met. The post-implementation results revealed that of the 15 extended families surveyed all extended family members responded positively regarding an improved attitude in coping with the SED child's disability. Therefore, an improvement of their

emotional reactions to the disability was acquired (see Table 5).

Table 2

Family Survey (Post-implementation) Results

We have obtained information and support in this area

Question #	Area	Response Yes	Response No	Specific Example Provided Yes	Specific Example Provided No	Examples Provided Included:
1.	My disabled child's capabilities.	15		15		Academic, social and behavioral resources
2.	Academic performance expectations.	15		15		Academic progress after behavioral success, realistic individual expectations
3.	Coping skills.	15		15		Respite, "down time", exercise
4.	Medical assistance.	15		15		Hospital resources, emergency plans, crisis information, medication issues
5.	Social support and networking.	15		15		Respite care and the "buddy system", monthly Saturday kickball game and picnic
6.	Management of emotional reactions.	15		15		Deep breathing techniques, time-out, counting to 10
7.	Legal issues.	15		15		Confidentiality, Due Process, State and Federal laws
8.	Understanding of each family member's needs.	15		15		Verbal communication, respite care, family cohesiveness, extended family assistance
9.	Crisis intervention.	15		15		Emergency plans, therapeutic assistance
10.	Advocacy and community resources.	15		15		Educators, therapists, hospital personnel, governmental programs

NOTE: 15 Extended Families Polled

Table 3

Improved Understanding Interview (Post-implementation)

Question #	Response Yes	Response No	Specific Example Provided Yes	Specific Example Provided No	Examples Provided Included:
1. Do you feel you have an improved understanding of your child's disability after attending the series of workshops?	15		15		Realistic expectations, individual needs feeling less guilty and less isolated
2. Do you feel you have an improved understanding of your child's disability after reading the newsletter series?	15		15		Feeling less isolated, resource materials, the "buddy system" network
3. Do you feel that your expectations for your child's performance are more in line with his or her capabilities after this program?	15		15		Academic prognosis, behavioral expectations, individual assessments
4. Do you feel that the workshops and newsletters have helped you to understand how medical, psychological and social areas can work together to address you and your child's needs?	15		15		SED teachers, respite care, consistency, advocacy

NOTE: 15 Extended Families Polled

Discussion

The implementation of the educative and social support network program was successful due to extended family members' dissatisfaction with lack of family integration. The program's philosophy and goals were clearly defined prior to implementation, thus providing a concise agenda for extended family interaction and support. Activities were facilitated under the direction of the writer; therefore, consistency could be maintained and extended family participation could be regulated.

Table 4

Resource Questionnaire (Post-implementation) Results

Question #		Response Yes	Response No	Specific Example Provided Yes	Specific Example Provided No	Examples Provided Included:
1.	Child management unit at local hospital	15		15		Resources available, behavioral interventions, academic expectations
2.	Hospital assessment and physician referral	15		15		Referral procedures, mediction implications, length of hospitalization
3.	Child & family counseling center	15		15		Family therapy, before and after school care respite, the "buddy system"
4.	Diagnostic testing and evaluation	15		15		Intelligence testing, personality inventory, academic testing
5.	Emergency and crisis intervention	15		15		Crisis plans, referral assistance
6.	Parent support	15		15		The "buddy system", group networking, family therapy
7.	SED Unit teachers	15		15		Academic and behavioral information
8.	Community referral service	15		15		Legal, social, academic and medical resources
9.	Legal service	15		15		Advocacy, State and Federal laws, Due Process procedures
10.	Economic assistance	15		15		Governmental assistance, social security, free community resources

NOTE: 15 Extended Families Polled

Table 5

Emotional Reaction Survey (Post-implementation) Results

Question #	Response Agree	Disagree	No Opinion
1. We feel less alone.	15		
2. We feel less depressed.	15		
3. We feel less angry.	15		
4. We acknowledge our child's disability.	15		
5. We are better able to cope.	15		
6. We do not blame ourselves for the disability.	11	2	2
7. We accept our child's disability.	11	2	2
8. We are realistic about our child's disability.	11	2	2

NOTE: 15 Extended Families Polled

All of the objectives of the educative and social support network program were met as a result of implementation. Extended families participating in the program received information and support regarding issues surrounding their child's disability which parlayed an improved understanding of the SED child's disability, knowledge of the medical, psychological, social and community resources available and an improvement in their emotional reactions to the disability.

Post-implementation statistics revealed that all 15 participating families felt they had an improved understanding of their child's disability, more realistic expectations for their child's capabilities and an understanding of the medical, psychological and social services available. The writer attributes this high achievement rate to the educative workshops and support group meetings with the extended family members.

The writer contends that program success was demonstrated through the acquisition of effective coping skills for extended family members. The results of the post-implementation survey showed that all 15 extended families felt less alone, less depressed and less angry regarding the SED child's disability. Post-implementation statistics revealed that 11 out of the 15 extended families participating in the program accepted their child's disability, did not blame themselves for the disability and were realistic about their child's abilities.

Recommendations

The educative and social support network program proved to be a successful plan to facilitate a better understanding of the SED child's disability and of the community resources available. The program stressed the significance of peer interaction and community assistance.

The following recommendations are brought forth as a result of the implementation of the educative and social support network program:

1. An introduction and explanation of the goals and objectives of the program should be reviewed before any activities are begun.
2. Throughout participation in the program, extended family involvement regarding the educative, psychological, medical and social programs available is necessary for the acceptance of the SED child's disability.
3. Extended family acceptance of the SED child's disability is possible within the confines of this educative and social support network.

The educative and social support network program is an effective and efficient curriculum which encourages extended family participation, acceptance of the disability, support and coping skills. This program can be implemented in other ESE programs and in regular education settings.

Dissemination

The educative and social support network program has been shared with the writer's ESE colleagues in the same school setting. Interest in program facilitation has been positive.

The writer has presented the results of the educative and social support network program to selected ESE educators

at other school sites. The program has also been incorporated into selected ESE settings within the writer's county.

The writer has been selected to present the practicum findings at an ESE inservice training session. This type of collaboration will facilitate networking among colleagues and peers.

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APPENDICES

APPENDIX A

COMMUNITY SERVICES AVAILABLE

Community services available

Agency Name _____ Phone _____

Services Provided _____

_____

_____

_____

_____

_____

_____

_____

_____

Family Members Addressed _____

_____

_____

_____

_____

APPENDIX B

FAMILY SURVEY
POST-IMPLEMENTATION

Family Survey
Postimplementation

Name _____ Date _____

Please check one box for each area and give an example.

Area	We have obtained information and support in this area	Please provide an example of how you have used this information
1. My disabled child's capabilities	☐Y ☐N	
2. Academic performance expectations	☐Y ☐N	
3. Coping skills	☐Y ☐N	
4. Medical assistance	☐Y ☐N	
5. Social support and networking	☐Y ☐N	
6. Management of emotional reactions	☐Y ☐N	
7. Legal issues	☐Y ☐N	
8. Understanding of each family member's needs	☐Y ☐N	
9. Crisis intervention	☐Y ☐N	
10. Advocacy and community resources	☐Y ☐N	

APPENDIX C

IMPROVED UNDERSTANDING INTERVIEW QUESTIONNAIRE
POST-IMPLEMENTATION

Improved Understanding Interview Questionnaire

Postimplementation

1. Do you feel you have an improved understanding of your child's disability after attending the series of workshops? ❑Y ❑N
   EXAMPLE/COMMENTS:

2. Do you feel you have an improved understanding of your child's disability after reading the newsletter series? ❑Y ❑N
   EXAMPLE/COMMENTS:

3. Do you feel that your expectations for your child's performance are more in line with his or her capabilities after this program? ❑Y ❑N
   EXAMPLE/COMMENTS:

4. Do you feel that the workshops and newsletters have helped you to understand how medical, psychological, and social areas can work together to address you and your child's needs? ❑Y ❑N
   EXAMPLE/COMMENTS:

APPENDIX D

RESOURCE QUESTIONNAIRE
POST-IMPLEMENTATION

Resource Questionnaire

Postimplementation

RESOURCE	We understand and know how to use this resource	Provide an example of how you would use this resource
1. Child management unit at local hospital	☐Y ☐N	
2. Hospital assessment and physician referral	☐Y ☐N	
3. Child & Family counseling center	☐Y ☐N	
4. Diagnostic testing and evaluation	☐Y ☐N	
5. Emergency and crisis intervention	☐Y ☐N	
6. Parent support	☐Y ☐N	
7. SED Unit teachers	☐Y ☐N	
8. Community referral service	☐Y ☐N	
9. Legal service	☐Y ☐N	
10. Economic assistance	☐Y ☐N	

APPENDIX E

EMOTIONAL REACTION SURVEY
POST-IMPLEMENTATION

Emotional Reaction Survey
Postimplementation

INSTRUCTIONS: Please check the statement (agree, no opinion, or disagree) which best describes your emotional reaction in each area to your child's disability.

	Agree	No Opinion	Disagree
1. We feel less alone.			
2. We feel less depressed.			
3. We feel less angry.			
4. We acknowledge our child's disability.			
5. We are better able to cope.			
6. We do not blame ourselves for the disability.			
7. We accept our child's disability.			
8. We are realistic about our child's abilities.			